DDDS Governor's Advisory Council Medicaid Transition Day Services Work Group Transcription June 3, 2015 10 a.m. – 12 p.m.

Members Present: Tessie Bonk, Marissa Catalon, Katina Demetriou, Susannah Eaton-Ryan, Brian Freedman, Terri Hancharick, Emmanuel Jenkins, Daniese McMullin-Powell, Barbara Monaghan, Kimberly Reinagel-Nietubicz, Thomas Rust, Angela Sipple, Sybil White, Gail Womble

Guest Present: William Monaghan

Female Speaker: This is Susanna. We're starting the meeting today, Emmanuel will be a little late, but he is coming, and -- will be here, but will be a little late, both are expected, any additions or changes to the agenda? Any comments on the meeting minutes? We just got the transcript this morning, so I will send it out to you when I leave here. I will try to do it today, but I won't be back in the office until tonight so it might be tomorrow when I send it out.

Female Speaker: Any method to that madness?

Female Speaker: The transcript? I spoke to Vicky about it last week, the transcript company they have to transcribe it and format it and I guess they get it back as quickly as they can.

Female Speaker: Hopefully they won't be employed in the future for something that's

time limited.

Female Speaker: That was Gail.

(Laughing)

Female Speaker: Actually, Susanna whispered it and I said it out loud. **Female Speaker:** Well, we won't know that for a couple of weeks.

Female Speaker: No.

Female Speaker: Okay. So last week, both committee chairs, cochairs and people from the governors advisory council method with Jane, the division of director, to discuss our progress and what to anticipate for the last couple of weeks. And I think Jane was very grateful and thankful for all of the week that was completed, she said that to both teams. She praised everyone contributing. I thought that was very nice. One of the things she was very clear about was that we're done, that's the end of it and in the case of both committees, whatever we have finished that's what they'll take. My take away on that was I would like it to be as comprehensive and complete as possible. I would rather not send partial work to her. So in order to do that -- but which we discussed at the last meeting, that was our final take on the draft and that we would format it and review it this week. So TC brought up something that was very important to her, one of the things we added when we go through, well point that out to you, and the other thing was about person centered planning, I said to TC we put that to bed four weeks ago, this is our ninth meeting. And the reason that we did as a group decide not to have presence center planning, in there, as a group we decided that was going to be part of the evidence and the look behind, TC tempt strongly about it, so I thought it would be important to give her opportunity to discuss that now and see one of the ideas was if it wasn't included in our official recommendation, we could send it along and state this information came in late after we did the work but we wanted the division to see it in

the event we wanted to add it and if they wanted to use it when they were creating training and evidence materials to be used for evidence. But essentially, what we decide today well do and well bring next week and turn it in. So however complete we are or not, that's what will go in as our recommendation next Wednesday. I want it all to be buttoned up but if it's not and that's the decision of the committee, that's the decision of the committee, so I just wanted to update you on that from the division director and how we ended -- how we ended up with something that we're going to talk about now, and I put these in four and five but maybe TC would you prefer to start with this.

Female Speaker: Sure Gail and I would like for this group to add the person center planning questions to the assessment, we feel as do a couple other people who are not reason is that the, we feel that the person center plan drives almost everything. The needs of the people in the workplace, physical needs, mental needs, emotional needs et cetera, these needs then drive what work how much work, the level of stamina to allow certain concentrated work supports needed et cetera, this then drives the elements of the work environment, for this assessment, we have used a top down approach on what people think C M S wants, a person center approached is an approach that will be accurate and practical needs in the workplace, I do understand that the assessment is complete but in the whole time we have been doing this, it just has hasn't sat right with me, there really hasn't been much, was always it's about the setting and we get to the look behind and then we'll look at the person center plan, well I think if people come in and for the look behind there should be questions about the person center plan because when you think about it, in my opinion, they go hand in hand and I think they should at least with the questions that we have put together, at least they, the providers will answer this and we'll have the look behind people have an idea what's going on with the person center plan.

Female Speaker: This is Susana, I think we always thought that the person center plan would be questioned in the look behind I don't think there was any. (Person Coughing)

Female Speaker: That is why when I raise my concern, I stopped. But if just and that was several weeks ago it didn't get out of my mind that we got this whole document based onsettings that sounds pretty bureaucratic, I've been an executive, a manager and when things come from a above they don't fit the feel. They don't fit the means of individuals working there or their clients. And I think it's regrettable that we didn't start with person center plan throughout the whole thing, but at this point I would think the best thing they could do is actually add these questions so we have some elements of person center plans in this document and I will say a little bit more kind of elaborate on what TC said, just if we have people and they have person center plans those plans are going to say what this individual needs, wants, physical, mental, emotional. Yes.

Female Speaker: Everything that they need and want and then you will probably get a grip of those and that will determine an environment or maybe not, it's not the other way around that the environment determines what the person wants and that's my concern about where we are going with this, I would like to see these questions added and -- the other two were Gary and John. And so, that was no decision, we don't come into

asking the question if we were to speak for all of them, maybe they thought they were, maybe they didn't, it isn't TC ask me.

Female Speaker: This is Susanna, I will speak from the transcript, I know that Gary was not in favor of the person centered planned, if anyone remembers it differently.

Female Speaker: I remember.

(Person Coughing)

Female Speaker: Gary changed from my understanding.

Female Speaker: So I absolutely appreciate the -- to consider the person center plan, I think Gary, I think it's unfortunate he's not here to represent a changed opinion, I think it will be important to -- I thought there was general -- among.

(Inaudible)

Female Speaker: The understanding is we are starting with the setting that C M S is allowing. (Inaudible)

Female Speaker: The starting point for settings would be a philosophy that C M S is promoting around working for their independence and having the opportunity for -- and it gets built up within that.

Female Speaker: Thank you, you said exactly the word I was missing. Do we want settings to be the guiding philosophy or persons setting plan to be the guiding philosophy where should it be.

Female Speaker: It's Katina, I don't disagree, that this should be person centered, but that's not where we are when we come to the assessment, this is a systems concern, the persons center plan, ELP whatever we call them, is the responsibility at this point for the support or the case managers. And only right now the individuals on the wafer required to have this, folks on the family support specialist, they are receiving the other services, are case or family support specialist are getting better at doing them, it's not the standard across everyone we serve and when I'm doing a self-assessment as a provider and we look at these types of questions, this is where we should be. I don't disagree. Not everyone have a person centered plan or a person center plan that looks the same across all providers, some ELP, some have service plans, employment plans, so I think this type of questioning for me is more about what they should be looking for when you talk about the settings and the choices and how does the person involved in that, I'm concerned -- when it's driven down to this.

Female Speaker: This is Susanna, one of the things that came up before that, as these assessments are being taken by providers, providers have no control over this, this is not provider driven, this is came management driven so that was one of the reasons why the conversation went away with it at that time.

Female Speaker: It's Katina, I don't disagree that everyone should have a person centered plan and that should be the backbone of what we do and how we drive service, that's not the environment we are walking into with this self-assessment, it should be the recommendations coming out, that's going to be eye opening to those processes. And I don't know how we get in there so it is identified, I think it's important I think the folks making assessments, this is a piece that is missing across everyone that's served.

Female Speaker: Don't you think they should have an idea where the provider is, shouldn't they have some kind of idea?

Female Speaker: If we ask these types of questions, there needs to be places for

comments on here.

Female Speaker: Sure.

Female Speaker: My response is going to be because I serve 85 folks that are in

family -- they are not receiving an E L F when they walk in my door.

Female Speaker: That's the answer.

Female Speaker: If it's a yes, no, a no is a no.

Female Speaker: Right.

Female Speaker: This wasn't supposed to be the be all end all, this is Gail, I hear what you are saying, we are not there yet, how long has it been that they are not there yet, it seems to me if we send in this document, people will quickly get some kind of plan that will serve as a persons centered plan, a lot of people have ELP's, I don't know if people who need them and don't have one, or if everybody does, I don't see why it's so hard to have a person center planned, one more point none of these questions ask the particular about some persons plan, it says indicate the percentage of the people who have plans.

Female Speaker: This is Susanna, that would have to be based on what how they are being funded, because did you hear what Katina said?

Female Speaker: That can be insert the in here for those who are --

Female Speaker: Just so you know, I have come out and said I'm in favor for it to be person center plan driven, when the group decided not to do that as a group, we moved on, I'm not apposed to this, I understand why -- this assessment is assessing requirements from C N S and it is assessing providers so if we're going to go in and start asking questions that providers have no control over, those questions need to be asked and I think they need to be asked loudly and in a very important way, but I don't know if it's necessarily this is the place for T I mean, if one of you want to tackle this clean it up, get it ready for us to insert, we can insert it, I doubt the division would leave it in because it doesn't speak to what the --

Female Speaker: I think we should.

Female Speaker: Who's going to do the work.

Female Speaker: I will do some of it.

Female Speaker: It has to be done to me by the end of the week because we are turning this in next Wednesday so that's the issue, my only issue about this was it was late? The game, this should have been brought up four weeks ago.

Female Speaker: Perhaps the answers we got shouldn't have been it was done for this particular reason and it's going to be handled.

Female Speaker: The committee.

Female Speaker: Agreed to that not me --

Female Speaker: You were the one who explained it to me after I was not at the meeting, I was -- and so -- it's still even though this group moves at a fast pace, that's when you get out of here that you have things pop off in your mind.

Female Speaker: Totally agree it happens to me every week, I'm sure it happens to everyone.

Female Speaker: I'm sorry that this is now at this stage, but I'm afraid I think here better late than never to have some section that deals with these questions.

Female Speaker: The entire thing on the CMS rule is to asses the settings that the

services are delivered into what they want to achieve I assume is that the settings are open to having the most available integrated setting possible for each individual. And if that's in place and the person centered plan is supposed to. (Inaudible)

Female Speaker: It's also supposed to be documented in the person centered plan and in deviations to the most integrated setting for each individual that's what CMS says.

Female Speaker: Even that Gail, how did the other group come up with basing it all on the person center plan if it's against the rule of CMS, does anybody know?

Female Speaker: Can you are speak to that?

Female Speaker: No because I think my understanding is that it's the most integrated community setting based on the person's choice. Because everything is founded on everyone on the waiver, having a person center planned.

Female Speaker: Not in residential services, when those questions come out to folks who are in living in foster, those folks probably don't have.

Female Speaker: A plan. **Female Speaker:** A plan.

Female Speaker: Well, so is there great harm in adding these questions? Wouldn't

you think these questions would be a plus than a minus?

Female Speaker: Bryan? Male Speaker: Yes. So.

(Inaudible)

Male Speaker: I feel like I'm at a bit of a loss because we just received these questions yesterday, for all of the questions -- we have gone through question to question, we patched things out, our team.

(Inaudible)

Male Speaker: The questions that are being brought forth so late in the game, I'm completely -- when we are there in the meeting it's not often the time you come up with the things you feel strongly about and -- I just have to say I do think it's challenging to have to come up with this at this point and I think it's -- thinking the questions through so you know, we have to wordsmith it. I'm hesitant to include anything this quick, very deliberate process.

Female Speaker: TC suggested that we extend our meeting next week which wouldn't work because we have to turn it in next week, what about having another meeting this week, are John and Gary going to be back.

Female Speaker: No. Uh-uh.

Female Speaker: So that kind of leaves us out of place, we have to address what

Bryan is saying.

Female Speaker: Well, can we do it being next week. **Female Speaker:** No we have to turn it in next week.

Female Speaker: So what's the reason we couldn't have an initial meeting on this 30

minutes earlier than the regular meet and go then have the final meeting. **Female Speaker:** What are we going to do with the information we gather?

Female Speaker: Like what Marissa puts up there. **Female Speaker:** She can't do that to this one.

Female Speaker: Why?

Female Speaker: If it's already formated, you should be able to import it, this is Kimberly -- for someone to volunteer to finalize the wording on these questions and if we go ahead and format them, then it should be a matter of minutes to input them into a form.

Female Speaker: This is Susanna. Can you do that Marissa?

Female Speaker: Sure, it can be added today or --

Female Speaker: Okay. So here is what we are doing. Bryan.

Male Speaker: Yeah.

Female Speaker: You want this to go through same diligence that all of the questions have gone through, so can we get this out tomorrow morning -- those of you who are willing to format this into a similar format of what we're doing, how soon can you have that ready for us to see, so we can get it out and review it, well do it as transcript comes to us within a couple of days.

Female Speaker: I cannot exactly say.

Female Speaker: Can I have it out to everyone by Friday afternoon so everyone can

view it over the weekend so when we come back on Wednesday morning.

Female Speaker: Yes.

Female Speaker: So is everyone willing to meet let's say 9: 00 on next Wednesday in order to discuss this so that we can then, do what we need to do to get it in? Can I see a show of lands, who will meet at 9: 00?

Male Speaker: Sorry checking my calendar, I should be fine to do that.

Female Speaker: If the discussion takes longer than 30 minute ands we get into a big

discussion --

Male Speaker: That was my --

Female Speaker: Well we all understand let me rephrase that, does everyone understand, wherever it lands it's going on, so we need to be concise with our thoughts, have the debate get through it and get it in there.

Male Speaker: This is Bryan, just to clarify, wherever it lands that's how it's going in, we haven't even decided if these questions are going in or all or some of them are going in.

Female Speaker: That's understood Bryan, whatever we decide.

Male Speaker: Right.

Female Speaker: We need to get it in.

Female Speaker: Those of you who had side meetings with John and Gary, are they

going to be here next week.

Female Speaker: I understand they will.

Female Speaker: Yes.

Female Speaker: I'm going to, because I have reread the conversation going through, it's Katina, when I read this thinking about maybe even switching around because you know, when you look at the last two points, they are something that are a question that can be asked, for those who -- it's asking you worded this appropriately, on the sample of those who have plans and that would be the key. Who have plans. Then that would be the first question, who have plans person center plans, how many of those percentage of your population from there the questions would be, for those who have plans, what percentage of the plans indicate the setting which they receive services -- I think we asked these questions in here, just a different way.

Female Speaker: Where would you see them in there already.

Female Speaker: It's about, do they have, with this one for example -- ho have a person center plan, please indicate the -- there are center questions on here, do they have choices in settings and services that each provider offers.

Female Speaker: It's vague.

Female Speaker: Your right it's absolutely vague, when we think of this, I think these types of questions, the person saying yes should be coming back to me with this, how many? What's your process? How do you make that happen? We can say it's an ELP, let's pull someone who has been at a meeting, their family, and they had an X Y Z choice, how was it documented, and if there is no choice, why not?

Female Speaker: I was going to say after they format question ands we have the final discussion on it next week if that's what's concerned, maybe the group can make a recommendation that something like this is part of the look behind process if they don't want it, and it doesn't belong in the questionnaire but the group feels strongly it's conveyed to the division as being a important part of the look behind process, it's not a perfect solution for everyone, but it might be a way to help the group move forward.

Female Speaker: I think it will get to the point here, it has to be brought to the forefront so if these are the types of the questions as a look behind you have data from the provider that you have X amount of provider out there, and this is the percentage of people that have the plans, why isn't it 100%, that's the question that goes back to the division, they have to defend them, they have to answer that question, it's -- we may or may not have it. But it's also as a provider to show how we are delivering the service what is our plan, our plan can look very different from an ELP to an employment plan to a community based plan, you know that's part of the problem here, there isn't continuity across everyone and what that plan looks like. But I would say this is what's going to give teeth to why doesn't everyone have.

Female Speaker: Katina, if Gail can just rephrase what you said, so we are all sure.

(Laughing)

Female Speaker: We said in the concept.

(Laughing)

Female Speaker: Gail can't.

(Laughing)

Female Speaker: Let Katina rephrase it in the context.

Female Speaker: I think it's important because what we determined is people have concerns, they didn't feel comfortable bringing them to the forefront until now, so I don't think it's in our best interest to have these discussions when people aren't understanding the nuances of those things going on.

Female Speaker: I think that's what was happening before we didn't understand is that what you are saying.

Female Speaker: I'm sure we don't know and we didn't before, I mean there's no question we didn't before because we have come to this point and now automatic of these concerns are coming up at the ninth hour, so clearly there was a lack of understanding before.

Female Speaker: Right I could, never understand why the setting and maybe it's so much more important than the person center plan, I just never got that, and I would ask, is this about the setting or the person center plan, it's about the person center plan and

the no it's about the setting and then when there's deviations then, they look to the person center plan. And I just from the beginning thought it just kept gnawing at me Gail and I talked about it.

Female Speaker: We can't change what CMS is requiring, if the other commit fee decided it's about the person not about the setting, that will be up to them to defend their assessment.

Female Speaker: If it's looking at the person as the driver other than the setting as the driver.

Female Speaker: They're asking about the setting, they're not asking about the person, as Katina said, I think if I can rephrase it, if the setting is in compliance, then it's about the service within that setting and that's the person center plan. Am I rephrasing what you said?

Female Speaker: Yes, that's --

Female Speaker: Does that ring anything, any bells with you that makes sense to

you?

Female Speaker: Well, this is Angie, if I heard it correctly if the settings, they're asking through this assessment, the providers to say whether the settings are in compliance by asking all of these questions when -- and you go further into or in the look-behind you look at these questions of the person centered plan, you are going to find out through those questions how many people actually have a person centered plan by providers. And that given to the division shows you know, very few are getting these person centered plans done through their family support specialist.

Female Speaker: It isn't required through family support specialist.

Female Speaker: That's why it's a hard way.

Female Speaker: It's not required yet.

Female Speaker: No and I think to your point is that we do want to bring this guard and say that folks should have well they do have ELP work, the people should have these person centered plans regardless living at home living on their own. But I want to go back to this self-assessment of the provider and it is about the setting and it is about how what CMS is looking for, agree these questions should be a recommendation in the look behind, we asked the question are they parts of the person centered plan, do they have a choice about the services, we have gone through questions, if the answer is yes, tell me how many of those folks have it? And these would be the questions, if it's no, why not?

Female Speaker: Katina, this is awe snarks I understand what you are saying, that is not solving the concerns of Gail and TC I don't think. They would like to see this built into the questions of the assessment am I correct TC.

Female Speaker: Yes.

Female Speaker: Okay. So just so every is clear on where the committee has some people feel one way and some people feel a different way, that's what we have to hash through in order to complete this and get it submitted. So Gail and TC have said they will I assume you work with Gary and John to get this ready.

Female Speaker: Yeah well -- --

Female Speaker: And you will have it out by Friday and we'll debate it next week. Unless there's some new information that you want to bring here to this debate.

Female Speaker: This is Angie, if I'm maybe I'm off base here because I don't know,

because I'm a parent.

Female Speaker: I am too. Female Speaker: I am too.

Female Speaker: All three of us are.

Female Speaker: My understanding through governor's advisory council and what I have learned is that these family centered plans, if we put these in here, we're saying basically, we're going to be identifying all these that are missing, family centered plans, my understanding is that we don't have them a lot of people don't have them because we don't have enough family support specialist to do them. That is what I have always heard unless I'm just totally way off base that's what I continue to hear and You find out myself that it's not in place because my family support specialist doesn't exist anymore.

Female Speaker: And that's DDDS.

(Talking at the same time)

Female Speaker: That's not the provider.

Male Speaker: This is not a DDDS assessment it's a provider assessment maybe we

should get together and do a DDDS assessment.

Female Speaker: That's why I feel.

Female Speaker: That's the point I want to make, this is Susanna, these are huge issues to parents, providers, the people who are -- I understand they are huge issues but I'm not sure it's an assessment of the provider setting issue. I don't know how -- and I understand this is an opportunity maybe to drive home this isn't happening, I think that's where you are coming from, I don't mean to speak for you.

Female Speaker: This is Angie again I think from what I heard in the governor's advisory council, they are aware it needs to be done, it's not that they are not being heard.

Male Speaker: It's the money.

Female Speaker: They don't have the money for all these family support specialist, yeah we need them bonings.

Female Speaker: This is Gail I'm sorry, you can't go by we just don't have the money, nothing would have happened, I worked -- that's exactly what you hear, we just don't have the money and there has to be a hard lobby if these positions are really needed and get them funded so that it happens, you don't work on a federal report with the idea in mind that we can't do this T we don't have enough people to do it. It's totally inappropriate.

Female Speaker: I'm sorry Gail, this is an assessment of the provider. Not of DDDS. **Female Speaker:** Yes, I understand that as you san in a, this is Gail, there's this question, how many people have an assessment and from there it comes to the fact that the provider isn't supposed to be doing and DDDS needs to do it.

Female Speaker: So how do we, I guess the question Angie said --

Female Speaker: I think it should be in the look behind, this is Angie, I agree it would be great to recommend to put it in the look behind and I think you are going to find out they are going to find out how many are being done by each provider by the percentages, they are going to see.

Female Speaker: Yeah, this is Gail, the rule is don't you have five years --

(Inaudible)

Female Speaker: The diagnosis would have.

Female Speaker: It's four years now, this is Susanna.

Female Speaker: So it's not like we would be putting something in there, if they didn't

do it in January DDDS will be shut down.

Female Speaker: This is Katina, if it's in the assessment, if you think about it on a score card which we don't have, it's a negative against a provider that discount have control.

Female Speaker: No it isn't. (Talking at the same time)

Female Speaker: It's not your job to do it --

Female Speaker: Every person should come with a ELP workbook or a formal ELP and then the provider should take that with the families and the individual whomever is at the table and develop how you are going to develop the service within what we all identified in this process. So I agree that this is very eye opening again, I think it comes back to the question, does it need to be in the root of it because it really isn't something that we can be assessed on, unless it was a rule saying every person entering my door I'm responsible to do that plan.

Female Speaker: That's not the case, that's not your job.

Female Speaker: Right, so why would I be assessed orphan it.

Female Speaker: Last week people who are getting the services from the providers to be assessed, maybe we can do an assessment, we were told it's too much time, now

we come up with a another survey for the providers, we don't have the time --

Female Speaker: We just table it, come an hour early, let the gentleman have their say and that's the end of it.

Female Speaker: Can we see a show of hands of how many people think this should

be in the look behind not as apposed --

Female Speaker: I think it should be somewhere.

(Raising hand)

Female Speaker: Not as apposed to right.

Female Speaker: I'm not saying as apposed to, how many people think these are important questions that should be somewhere it looks like everyone agrees it should be somewhere.

(Raising hand)

Female Speaker: This is barb, after the what do you mean by look behind. **Female Speaker:** The division with self-advocates are going to sample different

providers and look behind what the answers mean.

Female Speaker: Okay.

Female Speaker: That would be developed with questions like this.

Male Speaker: Can I see those?

Female Speaker: This is Kimberly, just to clarify, I don't believe the other group is deciding they feel some of their questions should be included in the self-assessment, I think their plan is to potentially identify which of the questions they want to recommend to DDDS so I don't think it's not out of the realm of this group as well to bring that guard if that's decided once we get the final questions from Gail and TC.

Female Speaker: This is Susanna it's on our agenda to decide about other recommendations we want to make. That's number five. But this was TC, so I felt like it would not be in the best interest of the whole team if we did not go back and look at

this, if anyone had anything they felt strongly about, it has to be addressed, we would like to be delivering a recommendation that's based on the consensus of the committee.

Male Speaker: This is Bryan --

(Inaudible)

Male Speaker: It seemed like we would not have the time to come up with questions for that type of survey, but that we would be discussing that we are boing to make a recommendation, it seems like -- any new ideas that come up come up with an Avenue new for delivering that message back to DDDS, but while also recognizing that -- come up with anything where we can have the process we have so far. (Inaudible)

Male Speaker: Recognizing the time we have available --

Female Speaker: This is Susanna, maybe we want to request from the division or the governor's council that we continue meeting this work group to hash out some of these things that we think are important that we need to address that we don't have time to address for this particular assessment recommendation, would anybody be interested to do that, I see some yeses and no's.

Female Speaker: This is Terry, a lot of people put it in the look behind, we would have time for that piece after words I would assume, correct?

Female Speaker: Well, I think -- I think the group was to talk about the entirety of the process during these last nine weeks. So I don't know how much time there would be for that, but you know, and.

Female Speaker: I just want to make a couple of comments, obviously, the division has not been silent about the fact that individuals who live at home with their families or live on their own don't have a plan, we know that, we talked about that in a variety of settings, it's obviously why we're moving forward with trying to obtain -- target a case management which would allow us to increase the amount of resources that we have -- support coordinator, it's why we had multiple stabs at trying to create a family support waiver, it's obviously something that we know. CMS in there -- all of their documents that they have submitted, they stated that their expectation is that the person centered plan process is already in place, they are not asking for information about that, they are assuming it's occurring, across the country, you can say that each state might be looking at the quality of those plans and I think, even if you look into some of the guidance that CMS admitted, there are additional items the states are going to have to look at, it's not just whether it's in the plan that it will be acceptable for a setting that's perhaps not inclusive -- that won't just be the arbiter, it's not just that it's in the plan, it will have to fit on the variety of other criteria and I think Denise has gone through that at a couple of other meetings, where they listed the different things that would have to be published in order to be proved as an exclusion, so it's not that an individual can participate in a setting that it's perhaps not inclusive, just based on the fact that it's in the plan, it will have to meet this other criteria. So that's all I have to contribute.

Female Speaker: Well, has everyone said their piece.

Female Speaker: This is Denise.

Female Speaker: Apparently Denise hasn't.

(Laughing)

Female Speaker: On the bottom number two talks about funding, can the provider do

the right thing without funding, I don't think that should be addressed at all, we have been -- DDDS we are not to consider the money that it will cost too much or anything else, you know how that financial backing and knowledge to know how to stick a fiscal right on anything.

Female Speaker: Point well taken, so.

Female Speaker: So that should not be included.

Female Speaker: So what we'll eliminate that in the discussion. Is everyone in

agreement that two is not appropriate for this assessment. **Female Speaker:** That will come up eventually anyway.

Female Speaker: It definitely right. Just to say to this committee, people are extremely concerned about the families, it's not about this piece of paper, it's about the well being of the people we serve, so the fact at this stage in the game we are looking at it and saying well, wait a minute, I think that's okay. I think that's our job, that was the task we were given, I wish it happened four weeks ago, just because didn't doesn't mean we are not going to address it now.

Female Speaker: Right.

Female Speaker: It's tough and I was feeling good about this looking done, you know,

too bad.

Female Speaker: I sent an e-mail and you called me saying what is this about.

Female Speaker: I said thanks a lot TC I was feeling good for a millisecond none the

less not to make light of it, it's very important for the people.

Female Speaker: Very important.

Female Speaker: For the people who are ultimately going to be living with the

consequences of this ruling.

Female Speaker: We know where it's headed, there's going to be a part of the

population that's going to get screwed, S-C-R-E-W-E-D.

(Laughing)

Female Speaker: That was TC. **Female Speaker:** No, that was Gail.

Female Speaker: They are going to be put in debilitation, that's a big concern, that's

another whole subject. That's why I'm fighting for this person centered plan.

Female Speaker: So. (Person Coughing)

Female Speaker: Just to sum up, we all are in agreement that it's not the

responsibility of the provider, to have a person centered plan, everyone is in agreement

in that?

Female Speaker: We knew that from the beginning.

Female Speaker: Some people think this should be in the look behind some people would like it to be in the content of the assessment. Gail and TC are going to put something together by the Friday so I can send it out on the weekend, so we can look at it, we are coming in 9: 00 next Wednesday so we can debate it, Marissa will be ready to plug into the actual content of the format if the committee decide we want it in there, it will be ready, Gail and TC will format it, and Marissa will plug it in, have I summed up? Is everyone okay with what I summed up?

Female Speaker: This is barb, I won't be able to make it next week, I have an executive meeting.

Female Speaker: This is Susanna, barb, would you like to send something out to the committee about how you feel about these things.

Female Speaker: Sure.

Female Speaker: I think it's important to everyone, if you have the group e-mail that I

send you, send out your feelings and we can have it here at the meeting. **Female Speaker:** I have to double check, I don't think I have a group e-mail.

Female Speaker: Okay.

Female Speaker: I mean I have the contact list in my book but --

Female Speaker: Okay.

Female Speaker: Just reapply to all --

(Inaudible)

Female Speaker: Okay.

Male Speaker: This is Bryan, so I want to clarify one thing, it sounded like there were the suggestion of removing question number two and did we come to a final decision on that

Female Speaker: Everyone agreed that was not part of the assessment this is

Susanna.

Male Speaker: I'm in agreement I just wanted to make sure.

Female Speaker: Bryan it's from the person centered plan document that I sent out from TC number two on that.

Male Speaker: Yeah, I knew the exact question, I was in agreement I wanted to hear, I didn't hear what the final decision was.

(Inaudible)

Female Speaker: Okay. We have up on the screen which I also sent to you, the only change in this was TC asked to include when we were talking about fading out services that it be about changing services not just fading out her concern was that as people age, they may need more or different services and she wanted to be sure that was apart of the assessment.

Female Speaker: Fading is also in here.

Female Speaker: Both are in here, changing is in there and fading.

Female Speaker: When I was asking the question last week I asked about fading supports and I didn't explain my concern clearly that -- the people I said age the fading supports they need, increased supports.

Female Speaker: So I just asked Marissa to include that I was certain that known on the committee was going to disagree that we have kind of hashed that information out about.

Female Speaker: Are there any extra paper copies of the final? I can't see up there it's too far away. Thank you.

(Passing out papers) paper

Female Speaker: So Jane said when we met with her last week we didn't need to elaborate on the directions because the division was writing directions, so we didn't spend time doing that. I went through every question I didn't see anything to put in the glossary, so --

Female Speaker: This is Terry, you did a great job on the formating.

Female Speaker: I didn't do it. Female Speaker: It's beautiful.

Female Speaker: We should all thank her, she did a great job.

Female Speaker: If everyone wants to look through quickly, with the exception we

added from TC it's the same as the previous one, it just looks good.

Female Speaker: Is it supposed to be is it somewhere else -- where is that?

Female Speaker: What page are you on Angie.

Female Speaker: It looks like we dropped one somewhere.

Male Speaker: That could be it --

Female Speaker: I'm looking at one to support access to the greater community.

Female Speaker: Okay.

Female Speaker: I'm just comparing the first one and the previous one, we have -- it

looks like we dropped one or combined. **Female Speaker:** Okay. I will look.

Female Speaker: Which drop are you looking at Angie, drop three.

Female Speaker: May 27.

Female Speaker: That's the right one.

Female Speaker: Comparing, it looks to me like F was dropped is there evidence that

visitors have been present at regular frequencies.

Female Speaker: It's E on page one. But it's here.

Female Speaker: Something is dropped.

Female Speaker: I will make a note, I will see what was dropped.

Male Speaker: So yes --

Female Speaker: There was miss lettering on page two of the other one, there's a D.

Female Speaker: Oh.

Female Speaker: If you see the letters aren't.

Male Speaker: I see there -- Female Speaker: Okay.

Female Speaker: So it looks like --

(Inaudible)

Female Speaker: Okay. So we're saying it's okay? **Female Speaker:** Yeah (Talking at the same time).

-- --

Female Speaker: I have a question.

Female Speaker: Because it's in here still, the way it's read I'm very concerned about S to A, did the individual have an opportunity to choose a day service setting from the variety of options, reading that it's still are we talking about within the provider that we are being supported by?

Female Speaker: Well clearly if the provider is answering it, it's going to be within that provider, you wouldn't be answering from me, so I would say yes to that this is Susana. **Female Speaker:** No, ma'am. I would say yes too, we have gone back and forth with this one.

Female Speaker: Can you see --

Female Speaker: Did the individual have the opportunity to choose day service setting, when you are talking about setting, it could be, it goes back to provider choice, if someone isn't sure all of the discussion we had around this question.

Female Speaker: This is Susanna, does it clarify if we say the setting offered by you.

Female Speaker: I think so yes.

Female Speaker: This is Kimberly, I have that noted we did change that language at

the last meeting.

Male Speaker: Okay, it was supposed to be a variety of options, offered by the

provider.

Female Speaker: Offered by the provider?

Female Speaker: Can you say that again for me please.

Female Speaker: Did the individual have the opportunity to choose a day service

setting from a variety of options offered by the provider?

Female Speaker: Okay.
Female Speaker: Okay.
Female Speaker: Fixed.
Female Speaker: Thank you.

Female Speaker: This is Denise. It should be put like that for the provider since the

provider is doing their own assessment. But what CMS had down is they are concerned that the individual had a choice between providers and between services offered both in those settings and settings that may be integrated in the community along with everybody else.

Female Speaker: This is Susanna, we had that conversation before, the answer is it's not the providers responsibility, DDDS chooses them recommends them based on what the person is asking for.

Female Speaker: Gail, how does that question get answered, does DDDS answer

this?

Female Speaker: Seriously.

Female Speaker: Gail, I think to the group, I think again to reiterate this question, if you're asking us as providers in this self-assessment among all services, community based employment, did the individual have a choice an informed choice to be where they are currently placed and it's another question in here, if other opportunities provided itself to be part of that process, I think it makes it clearer when the look behind is going they know it is within the agency that's filling out the information.

Female Speaker: Yeah, that's fine. My question was a different one. Is there another place that this question that CMS is asking for is posed, another place that this provider is not responsible to know what ten other providers have but somebody is the umbrella.

Female Speaker: And that's DDDS this is Susanna, you are asking is DDDS going to

be assessed? (Laughing)

Female Speaker: They have to be.

Female Speaker: I think that is the question.

Female Speaker: I guess that is.

Female Speaker: DDDS as you all know is not perfect. We know that there is work that we have to do as well, obviously we are assessing ourselves exactly. This particular document is an element of the assessment process. We're looking at this document, this document is looking at the providers and the settings, DDDS has it's own task.

Female Speaker: Will that be going back to CMS because I'm acquainted with a situation of a young man not having ready supports for himself who was being

transferred from a place where he made money to one that would be volunteer, I don't think he understood it, and I don't know if anybody explained it, and it was from -- it was going to be within that provider and I don't think it was ever explained to him, there's a place over there outside of this provider, where you can continue perhaps to pack boxes or do something else, but that's.

Female Speaker: But that's not the providers responsibility. **Female Speaker:** But it goes back to Denise's question.

Female Speaker: This is Susanna -- based on what you said that this is part of the DDDS assessment that makes what TC and email are saying, they want all of this stuff in here all the more important and meaningful to those people who have said it should be in the look behind, if in fact this is assessing DDDS.

Female Speaker: I did not say that, it's assessing the provider and the settings, not

DDDS.

Female Speaker: All right.

Female Speaker: The other piece of that part of the question may be, are people in the day program or the provoke offered an opportunity for employment. Is there.

Female Speaker: Well, that's the law, and that's in there.

Female Speaker: Somewhere I think.

Female Speaker: Right? I think we have already put that in there.

Female Speaker: Okay.

Female Speaker: But is it only through that program or through others?

Female Speaker: Once again, that goes to DDDS, I mean.

Female Speaker: Yeah it does, to do the question, I would see that as being

answered -- (Inaudible)

Female Speaker: And that would entail it's a very broad piece, but if someone were to ask me, I can say yes if they wanted to dig down, can they choose to be in the employment program, prevoke or day has been program I would have to say yes and then it would have to go back to where is that document?

Female Speaker: Are they offered an opportunity to go outside to another employment, although you are not the person to find that, you are the person to let them know there are options.

Female Speaker: That's what Gail said.

Female Speaker: That's not the provider, that's the case manager.

Female Speaker: Well, yeah, that's me saying somebody else can do it better over here, if you are not happy with me, please speak to your case manager to look at other options.

Female Speaker: It's the -- you know you're currently employed at wall greens and you are ready to change that job, you want to change it, you're volunteering at the food bank and you want to talk about a different volunteer option, it's those kinds of internal provider supported kind of activities.

Female Speaker: Absolutely.

Female Speaker: What about external ones that's what we keep going back. **Female Speaker:** We definitely need to know there's work to do no doubt about it. **Female Speaker:** This is a place to kind of open up and look at all of this, not to say you have not done X Y Z, lord knows I have worked with agencies, no matter how hard

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we tried, we couldn't do X Y Z, this is a place to look at the thing ands have them -- the parts that are important and get support for DDDS not from this group and this room but maybe from some others maybe from people but not as this group to be able to move forward if there are things that are necessary and are missing. And I do know how budgets work and that Jane can only put in the budget what she has allowed and some of that is taken out and I know about the whispers that come down don't ask, there's nothing in paper anywhere and I'm not trying to place her in a bad position, there may need to be some effort from another entity to show DDDS up.

Female Speaker: I guess this is, this is Susanna T we tried very hard from the beginning to stay focused on the task of this committee, as we are winding down, all of those things there are a huge concern are coming to -- and maybe that's a good thing basically that was not our task. So I think just getting back to the task at hand is -- and as I said before, maybe there needs to be an additional committee or people put together who will tackle these things. I think I said before that I have said in other group settings, I thought the look behind was the big issue at this point and that we should be focusing on that and who's doing it and how it's being done, that's not our task here either.

Female Speaker: This is Denise, this is kind of a little bit -- it doesn't fit I know one B says this setting located in the same building or same campus as an institutional treatment option, if high or why not --

(Laughing) (Inaudible)

Female Speaker: It's the only one that --

(Laughing)

Female Speaker: Denise we tried to comb through them and identify them, that be

pulled out and apparently we missed one.

Female Speaker: Shouldn't it be if you ask why?

Female Speaker: Yeah. Female Speaker: No.

Female Speaker: There isn't any reason why.

Female Speaker: Right.
Female Speaker: It's just --

Female Speaker: We are trying to find the ones that are absolute.

Female Speaker: I disagree with the if you are, then you are not complied, because

other states have gotten approval for compliance for being on facility.

Female Speaker: This is Denise, I wasn't aware of that -- I know they are fighting for it

and all that.

Female Speaker: They got approval, my understanding is they --

(Talking at the same time)

Female Speaker: This is Denise. I'm familiar with that, they are way out in the

middle of nowhere, -- Delaware can't count on that.

Female Speaker: Right. Female Speaker: 300-miles.

Female Speaker: It needs to be there, in there because there may be some justification for whatever the question is, and if you don't even allow it, they

automatically (Talking at the same time).

-- -- .

Female Speaker: We are going to insert -- if yes then why, is everyone okay with

that?

Female Speaker: Anything else?

Male Speaker: This is Bryan, so one general question for this that came up from last

meeting -- (Inaudible)

Male Speaker: We are not going to be creating directions, maybe that will be included in directions and then last week, it was his understanding, Gary's understanding that this survey will be completed for each individual employment site, that a provider might have in person, but might be supported a person -- (Inaudible)

Male Speaker: And that was my understanding was if you were a provider and you were conducting support -- that you would be filling out one survey, but I wanted to bring that back to the group, we talked about it briefly in the last meeting -- I just wanted to bring that up, maybe that's not for this group to discuss but -- it was some concern that Gary expressed last week.

Female Speaker: Do we speak to that Marissa, I think.

Female Speaker: I think it's going to be important that the instructions that are part of the process are very clear so that folks understand that there is not no confusion whether this should be assessed at all supportive employment settings or not. I think it needs to be very clear what the expectation is, how this survey is administered.

Female Speaker: This is Susanna, so we don't know yet or do we? **Female Speaker:** I think the instructions need to be clear about how the assessment -- not knowing exactly how things are going to be structured is just important to know that we need to be very clear about our expectations on how the tool is administered.

Female Speaker: Didn't James said we don't have to do the instructions, the.

Female Speaker: The division.

Female Speaker: We can make recommendations.

Female Speaker: To those directions.

Female Speaker: And definitely will be a conversation that there was some confusion about whether or not this assessment would of had to be done at owl supported employment locations or not.

(Laughing)

Female Speaker: That could be challenging, this is as you san in a --

(Laughing)

Female Speaker: There's a bunch of challenge on that because we are talking about employment, and we're talking about imposing the state representatives into someones business, and I think I will go on record and say they better consider that very carefully, we at this point, we don't have you know, we have the employer that we have to respect their environments as well, and the person that's working there may not want someone to know -- I don't know.

Female Speaker: Yeah.

Female Speaker: Okay. We are getting way far field here.

Female Speaker: This is Angie, are we assuming in this assessment -- directions if

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the individual cannot speak or be able to communicate or participate, then the families will be the ones to participate, when you ask any of the questions, does the individual have an active role in developing the persons center service part? An active role, are we assuming if the person is unable to that the family --

Female Speaker: This is Terry, if they don't speak doesn't mane they don't have an active role.

Female Speaker: I see where you are coming with that question.

Female Speaker: I would answers yes, it is a team approach and someone is advocating for that person, they are there to be part of it if they choose to be, if it's the right place to talk about or their family is there or a sibling is there, a guardian, so I think it's how the provider is engaging the person that we're serving is what the root of that question is, so if the person is not able to or doesn't want to participate it's their advocate that should be sitting at the table.

Female Speaker: I'm wondering if that's something, this is Angie, if in the directions or, I don't know.

Female Speaker: This is Susanna, I think I think, Gail stepped out but -- we can rediscuss this when she comes back, we are going to be delivering our recommendations next Wednesday, as a committee, we need to decide what's most important to do now to have in what we deliver. That's what's on the agenda, so when you bring up questions about the directions, that's one thing do we want to make recommendations about that, we now have this meeting and the next meeting to decide that, get it written by whoever is on the computer and deliver it next week so we have that, we have the person centered plan which we know it's going to take time, people feel passionate about that, we have look behind recommendations, evidence recommendations. And self-assessment. Those are all of the thing we are considering now, we need to establish how we are going to spend our time which I think this is to put priority on and how we are going to spend our time making decision ands getting it incorporated to next Wednesday, I want to wait for Gail to get back, she feels strongly about this stuff, I want everyone to weigh in, I want to repeat what things are on the table now that are going to be in the recommendation aren't depending if we are going to put time, the directions, person centered plan, look behind, evidence and self-assessments, that's five things that various people have different attachments to each of those or feel importance about each of those things. So I think it's key that we decide how we want to spend our time whether or not we already said well extend our meeting by starting at 9: 00 next week. Anybody want to weigh in about that.

Female Speaker: We are speaking about the person centered plan, that question does talk about the person centered plan, can we include that when we are talking next week, to see if someone will be with them when they have an active role, you want to add that --

Female Speaker: I think that question was answered.

Female Speaker: Was it?

Female Speaker: Didn't Katina answer that question?

Female Speaker: She said we would -- I heard her say we would, it would be a team

approach so we would always have the advocate if the person wasn't able to.

Female Speaker: Speak.

Female Speaker: I'm sorry I thought you wanted to add that onto the guestion? That

your question was answered and you don't want it added on?

Female Speaker: You are afraid Susanna is going to yell at you.

Female Speaker: I'm not afraid to be yelled at. **Female Speaker:** She gets it all of the time.

Female Speaker: I just, I guess I'm worried that individuals like my case who don't have the ability to speak out or communicate in some means would get by passed in some of that planning or their advocate whether it be mom or dad or sibling or someone else, gets bypassed that role when you ask those questions.

Female Speaker: You know, I know that Katina and -- are going to do that, I'm part of the team when we do the ELP and all, but I don't know that every family knows to be making sure that's occurring or every provider is doing that, I don't know. So should it be in there in those appropriate spots here where you say individual --

Female Speaker: There was a couple places in these questions.

Female Speaker: Okay, page three.

Female Speaker: Where you might want to put in there or you can, it may be a disclaimer, disclaimer might not be the right word, in the glaziery it may have to be somewhere.

Female Speaker: That's what I'm thinking.

Female Speaker: In the event the individual chooses to not participate or able to.

Female Speaker: Or not able.

Female Speaker: Or express or articulate their hopes, dreams desires.

Female Speaker: That the an advocate needs to be part of it.

Female Speaker: And I think that probably should be a footnote or you can do it as a

footnoting.

Female Speaker: Because that's huge.

Female Speaker: Do we have an assurance that the person has been asked to be

apart of it.

Female Speaker: That should be apart of.

Female Speaker: Then it's important that the person has been asked to be apart of it. **Female Speaker:** In my view, there's two different things there, because some of the things sometimes can be not appropriate, well, that's my view as the guardian and the parent. That I would prefer him not be apart of it so.

Female Speaker: I think we are getting into the nitty-gritty on an individual base, we do ask the question, do you have the policies and procedures in place to have the person involved to communicate, I think we asked those questions, if someone comes in and says okay what do we do for a person like your son, show me how that family is involved in the process and if they want to get down is every provider doing what they say, those are the questions that should be asked.

Female Speaker: This is Susanna, Gail is back, so I want to go through this again, we have five things still on the table. And I want to be sure that we allocate the appropriate amount of time or that we have enough meeting in order to get this done I'm not suggesting that we don't discuss it, I'm suggesting we prioritize it with all five things, person centered planning, directions, look behind, evidence and self-assessments, these are all things that we want to determine whether or not we want to make recommendations and/or changes, we have another 40 minutes here and we are scheduled nine to 12 next week. Can we prioritize how we're going to spend our time

so that everyone, the consensus is made that everyone is satisfied with what we're recommending and handing in next Wednesday. Angie you want to take that.

Female Speaker: This is Angie, I won't be here next week sorry. I'm on vacation.

Female Speaker: Can you send us.

Female Speaker: And I'm going on vacation.

Female Speaker: Can you send us information if you would like us to have it.

Female Speaker: But I think you know where I stand on some of these things, but I do think there should be a footnote somewhere regarding if the individual is unable to communicate it needs to be.

Female Speaker: I think we have to be careful with the word communicate. **Female Speaker:** It's unable to participate that's the word it can be medically,

something that can upset the person, you know.

Female Speaker: I agree. **Female Speaker:** Okay.

Female Speaker: You know, I think it's participate. **Female Speaker:** Participate should capture it.

Female Speaker: It doesn't Gail, just quickly, doesn't this cover the -- does the individual have an active role in developing the person centered plan, legally can't the quardian stand in for the person.

Female Speaker: But I also respect Angie's point in this, she is coming from the place she has a voice but she's thinking in a whole of families that doesn't have that active family member or guardian that a provider might say, we are having this meeting and we are in compliance right, because we have to be and if we are getting to this level and this is about self-determination and being in compliance, do you have a process when you are sitting at a table the person has choice and whoever is representing it, so a footnote of someone however we word it, I think a footnote would be appropriate in this situation.

Female Speaker: Right.

Female Speaker: And participate sounds great.

Female Speaker: So we are recommending putting a footnote at the end of this

assessment that talks about.

Female Speaker: If the individual serve is not able to participate. **Female Speaker:** I have an issue with not able to participate.

Female Speaker: Because it may not necessarily be in the sign off meeting, but they should be participating in the process and that might look different for people who don't have words but communicate in another fashion and if they are, medical, there should still be some level of participation in developing the plan.

Female Speaker: I agree with that. Female Speaker: I know you do.

Female Speaker: It's that interpretation of how it's read so it has to be discussed. **Female Speaker:** The thought of that something might upset them, isn't that more of a

reason to be there if they are upset to vocalize what they are upset.

Female Speaker: I had people saying I don't want my daughter or son in here, we have to honer their wishes, that's the point that's the planning, we are getting into details there, so we limit the amount of stress.

(Inaudible)

Female Speaker: This is Angie. I could opt Jacob out of the planning process if we are going to talk about the booth room and wiping or detail there which I wouldn't as a quardian, I don't want him to be embarrassed by that.

Female Speaker: So that's the kind of --

Female Speaker: Okay. Do we, do you have the minutes Marissa.

Female Speaker: Nope.

Female Speaker: Do you want to -- does someone want to address the wording of

that so we have that, so we can put it to bed, yes? No?

Female Speaker: It probably shouldn't be.

Female Speaker: It's not given to them, it may be to you, they don't seem to think Angie feels like this is not a given, if you look at the CMS stuff again, it says any deviation has to be addressed by a person centered plan, if it says in a person centered plan that this person can't do this or that or it takes this or that to complete a task, then that would be addressed there and that would be a qualified deviation from being in compliance, that's a lot of words and sounds confusing.

Female Speaker: I don't know if that addresses Angie's concern.

Female Speaker: This is the way it is, everybody has a say unless it's in the person centered plan, that should be the footnote, there's been the discussion between the family and all as of what happens to this particular person and the reasons for it and all of that, that would be part of the person centered planning and that would be okay to deviate from whatever the compliance is if it was just that one sentence and less contra-indicated by the person centered plan .

Female Speaker: I don't know. Female Speaker: People?

Female Speaker: It's too hard to be so general with this, because we are constantly, this is a moving target with services and the person that to just go back to say that there's a deviation, there may be a deviation for one meeting but another one there may not be, I guess the question for you is when you look through these, do you feel as a parent, that someone answering these questions would not take into consideration that you may be standing in on behalf of jab would be is that your concern.

Female Speaker: Yes, that is my concern in reading some of these.

Female Speaker: So how would we resolve that Angie what would you suggest. **Female Speaker:** I think there should be a footnote in, I don't know how you do this, if the individual cannot communicate the advocate/family should be part of the process., maybe something like that. I don't know. That's the way I see it. It always -- if the individual cannot communicate or --

Female Speaker: It isn't just communicating --

Female Speaker: That's not really. Female Speaker: Participate --

Female Speaker: I mean, mine is always communication. Mine is always

communication.

Female Speaker: Right.

Female Speaker: We have something in here about having an active role, and we say

if no, why not.

Male Speaker: There you go.

Female Speaker: You can say because the guardian under.

Female Speaker: Right under three U. **Female Speaker:** Page three and four.

Female Speaker: I'm looking.

Female Speaker: The new one. Do they have an active role, if no, why not? That's

where you can say, stress, whatever, but then the guardian.

Female Speaker: Because of other barriers.

Female Speaker: But -- can I clarify, are we talking about the role of a legal guardian

or are we talking about the role of a family member who is not a legal guardian?

Female Speaker: I'm talking about a legal guardian, family member.

Female Speaker: So the -- if there is a legal guardian, they are the ones who make

the decisions about the person's services, supports and the plan.

Female Speaker: Right.

Female Speaker: I mean, that's -- the legal if a person is someone else's legal

guardian, they then become the decision maker, not the person.

Female Speaker: So can you add does the individual and legal guardian have an

active role?

Female Speaker: -- (Talking at the same time)

Female Speaker: That the guardian, the legal guardian then tacks the place of the individual and the expectation is the legal guardian is working on behalf of the person. **Female Speaker:** This is Angie, again, those are expectations assumed I think. That the legal guardian is doing it or that they have been asked by the provider to be apart. **Female Speaker:** If there is a legal guardian, the legal guardian has to be part of the process, they then become the person making the decisions. So there cannot be a decision about the plan unless the legal guardian is part of that discussion. Just like there can't be, for a person that doesn't have a legal guardian, there can't be a decision about the plan.

Female Speaker: I'm sure it has taken place all of the time.

Female Speaker: Doesn't the guardian have to sign it in addition to the person.

Female Speaker: Yeah.

Female Speaker: There's a difference between a legal guardian and perhaps somebody that's representing their loved one whether it's the son or daughter or some other family member, if it's a legal guardian, there's a court order they then take the place of the person in making the decisions.

Female Speaker: Does that resolve that for you Angie?

Female Speaker: No.

(Laughing)

Female Speaker: Go ahead move forward.

Female Speaker: Okay so back to how we are going to spend the rest of our time, we have five they thinks we are looking at. Does anyone want to recommend how we have, we have essentially, three and a half hours left of this committee. So we have five things that are of importance to a variety of people on this committee, we know we are going to start 9: 00 discussing the person center plan and Gail, and TC are going to, Gail and TC are you going to take these one A through C, and just clean those up for us, or are you going to change them? What are you thinking.

Female Speaker: We are going to try to make them to fit the format of the others not

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change them.

Female Speaker: Just format them.

Female Speaker: Yeah.

Female Speaker: My recommendation would be not to put in refer to table developed

unless you are going to develop the table.

Female Speaker: Right.

Female Speaker: So if you clean them up in that way, that would help so it's a

concise recommendation.

Female Speaker: This is Terry, I need to understand, you are going to clean them up

bring them back we are going to decide.

Female Speaker: They are going to give them to me on Friday I'm going to distribute them so you can review them over the weekend, so on Monday well review them --

Female Speaker: That will include --

(Inaudible)

Female Speaker: Correct, so it's going to be here so that we are clear on this, because we have a short amount of time Katina, do you want to offer that up to everyone.

Female Speaker: I was saying in here somehow, when you talk about those who have plans, I think in the question or maybe, if you're answering yes or no, a place for it to say who may be developing those plans. If we're going to go down this rout, is the plank provided, because some of the folks that are leaving at home some of the providers do ELPs that everyone is served, I think it's important that's captured on the same size we want to recognize what's not being done, we need to recognize when it is being done.

Female Speaker: Okay. I'm sure Gail heard that and will take it under consideration.

Right?

Female Speaker: Yes.

Female Speaker: So they are going to provide us with information, send it out on Friday, have the weekend and Monday to look at it, we are going to decide whether we want them in there at all, do we want it all, or in here, in the look behind, we are not going to debate it, we are going to make those decisions so can we do that within an hour.

Female Speaker: Fifteen minutes. Female Speaker: Five minutes. Female Speaker: That's up.

Female Speaker: I'm fine with a vote, but I think people.

(Talking at the same time)

Female Speaker: What is your vote Angie.

Female Speaker: --

Female Speaker: It should be in the look behind.

Female Speaker: Gail what did you say.

Female Speaker: It should be in the look behind.

Female Speaker: --

(Inaudible)

Female Speaker: I was just saying, I don't have a lot of discussion to make about this, there might be people in the room but not me, I think after all today and people reading

it and over the weekend, I think people are going to come in here well formulated what they want to do.

Female Speaker: Okay so we'll say nine to 930.

Female Speaker: And you are going to cut off the discussion at some point.

Female Speaker: If everyone is comfortable with that.

Female Speaker: I'm comfortable with moving it guard because, and I will say this repeatedly, whatever we don't get down doesn't go in, so it behooves all of us to do our homework and we want it to be in if it's important, that's what I think Gail and TC are concerned about, there are things that they are concerned about that weren't given a

voice. Okay that's that, nine to 930, directions look behind, evidence and

self-assessments. What is important to people in this group that we recommend or

provide in what we deliver at 12 clock on the tenth?

Female Speaker: I have a question.

Female Speaker: What are we doing about the look behind? We are talking about

it?

Female Speaker: That's what we are deciding, if we are going to make

recommendations about it.

Female Speaker: Are we supposed to?

Female Speaker: We can.

Female Speaker: Are we allowed.

Male Speaker: We can make recommendations.

Female Speaker: That you think.

Female Speaker: So which they thinks do you feel strongly about and we need to get

in the packet we deliver, does anyone have. **Female Speaker:** Person centered plan. **Female Speaker:** We already discussed that.

Female Speaker: Directions, look behind, evidence and self-assessment.

Female Speaker: Self-assessment is this, correct?

Female Speaker: This is the provider assessment so we're talking about making a

recommendation about a self-assessment.

Female Speaker: And account recommendation be that we table that --

Female Speaker: It can be whatever we recommend.

Female Speaker: Got you.

Female Speaker: And want evidence, what are we discussing about evidence?

Female Speaker: I think it would be a fairly high leave of it wouldn't be -- **Female Speaker:** You will be thinking about that over the weekend.

Female Speaker: I thought before it yet let Terry tell you.

(Laughing)

Female Speaker: I think that's going to take time.

Female Speaker: Maybe we should put -- some we might skip.

Female Speaker: That's what I'm trying to do.

Female Speaker: We know the person centered plan is a hot button.

Female Speaker: The Ed is something --

Female Speaker: Okay but as apposed to self-assessment and look behind.

Female Speaker: My concern is the look behind, my second issue is the look behind, I feel it's important that we recommend how we think the look behind would be most

effective. In my opinion, because really, this is a recommendation, and what we talk about the look behind, once this is done, it's all about the look behind. And if we don't, we can recommend what we think.

Female Speaker: So let's do that, so.

Female Speaker: So well have a half our discussion about look behind 930 to ten.

Well write something, what?

Female Speaker: A half hour, I think we are going to need more time, we are going to come to the table with some ideas, I think there's going to be some discussion around that.

Female Speaker: Okay. Everybody, I encourage you to have your positions ready

on this, because we are done at 12 unless you want to extend the meeting.

Female Speaker: If that's the --

(Laughing)

Female Speaker: It's just a matter of you state yours and well take a vote is everyone

comfortable on that?

Female Speaker: Okay.

Female Speaker: Welcome to the table on how we stand, Angie, do you want to

designate your vote?

Female Speaker: Do you want to look at all of the material and volt ahead can she

vote ahead of time after looking at the material? **Female Speaker:** While you're on vacation.

Female Speaker: I'm going to recommend that we have a hour for the look behind. I

just think.

Female Speaker: Okay 930 to 1030. If we are doing a voting on this.

Female Speaker: I'm going to tell you this, 1130 to 12 we are putting it all together, we are done at 1130 everything get in and we are done unless we are extending the

meeting, nobody is say let's have a longer meeting.

Female Speaker: Let's have a drinking lunch.

(Laughing)

Female Speaker: So we have one hour left -- to does evidence, and self-assessment. **Female Speaker:** I think the evidence is going to be discussed in the look behind.

Female Speaker: So it's look behind and evidence. **Female Speaker:** And what was the other one.

Female Speaker: The directions we already, it's been said the directions are being developed, the recommendation to those directions I don't think we already captured some of these pieces so I don't think there's going to be a lengthy discussion about that, that's my opinion.

Female Speaker: Isn't there some phrase from your lips to Gods' or something.

Female Speaker: That sounds good.

Female Speaker: That would be good I thought we were there before and we're not, I think it's important to be sure that people have the time to say what they want to say before we put it in.

Female Speaker: But I also think you heard it from Jane, the directions are being done by them, so if we should not spend a lot of energy on that if the idea is they are already working on it.

Female Speaker: Okay is everyone in agreement with that, remember next meeting

it's going to be vote yes or no and move on.

Female Speaker: When we get the real deal from DDDS on this assessment like what they are going to accept.

Female Speaker: They have come back and said well be able to look at what they are going to give out before they give it out, but did not say when Marissa is -- I don't know if we are going to have a wrap meeting later or something saying this is what DDDS did with our 12 weeks of work.

Female Speaker: I think it's a meeting together.

Female Speaker: So if it's okay, this is Terry, I will be happy to put a self-assessment

together and get it to you and you can get it out.

Female Speaker: Excellent.

Female Speaker: Great, thank you.

Female Speaker: If there's a lot of discussion we table it and do it afterwards.

Female Speaker: Good good good.

Female Speaker: Thank you.

Female Speaker: So we are going to do the person centered plan from nine to 930, 930 to 1030, look behind and evidence. Well do the self-assessment from 1030 to 11 and Terry is going to provide that to us. And then from 11 to 1130, what do you think, well leave that open?

Female Speaker: Directions?

Female Speaker: Well, no, we are going to do one sentence on directions.

Female Speaker: Right.

Female Speaker: Well, no one disagreed with Katina, we all know it's going to be the division writing the directions so why put a lot of effort into that, does anyone disagree. **Female Speaker:** I thought we talked about I have noted in the same manner, we want to make sure these things are recommended to the division to consider the directions, in the same manner not receiving it should be asked, the legal guardian role, the locations and the conversation how it's administered is that it, are those the only they thinks you want to include in recommendations in the directions?

Female Speaker: Okay. That's all we have then. All right. So what we are going to do from 1130 to 12, we are going to have it up on the screen, look at it and send it in. Then go drinking. A few of us are going some place afterwards definitely.

Male Speaker: This is Bryan, Terry. **Female Speaker:** Thank you, Bryan.

Male Speaker: We can talk later how to form late that.

Female Speaker: I can put something together send it to you, you can add on and

edit.

Male Speaker: Thank you I appreciate it and I also vote that Jane take us out to lunch

afterwards.

Female Speaker: Hey, here, here.

Female Speaker: Only if she is using personal funds.

Female Speaker: Who invited her.

(Laughing)

Female Speaker: I don't know I think it was you.

(Laughing)

Female Speaker: It's a quarter of 12, since it's been a very lively discussion today, I'm

sure that our guests who don't generally don't have things to say must have something to say, come on you have come to every meeting and haven't spoken up.

Female Speaker: Better ask for forgiveness than permission, right?

Male Speaker: I would like to recognize the effort you have put in, obviously, you take this project seriously, and I appreciate your time and commitment to that, I also need to apologize for not being more involved in this process up until now, I need to -- I apologize to you for that, the comments I have regarding some of the things you were asking people about what's important, I have thoughts around that. Directions for the survey, I believe are more important than the survey. Let me say that again, I think the directions for the survey are more important than the survey, when you start doing surveys, I think it's important that the surveyor be consistent. In a way that the way the survey is applied and let me take you back to my personal world, when -- there are certain surveyors are focusing on one thing, other comings in you can careless, they are driving their nail deep, it creates inconsistency in the survey. Person center, I'm disappointed you chose settings rather than person centered -- .

Female Speaker: We didn't -- you don't think so. **Female Speaker:** Person centered, I don't think --

Male Speaker: In the conversation person centered -- you guys chose settings as the driving force, if I misheard that, I'm sorry.

Female Speaker: I don't know what you mean by they chose person centered -- it goes back to it being the person's choice where they choose to live. That's, I mean, Bill is the coach here, he can speak to it as well as I can, to say that each question goes back to you know, is this explicitly written in the person's centered plan, every question does not say that, but there is an understanding that the person centered plan is the justification for the evidence and the responses that are provided.

Female Speaker: And I think that's the same here.

Female Speaker: Yeah.

Female Speaker: Right, I'm just trying to say, I don't know what you said a couple of

times in the meeting, we have chosen person centered,. **Female Speaker:** We are looking at the settings like us.

Female Speaker: It's all based on what the person chooses.

Male Speaker: Choice, right.

Female Speaker: The question themselves most of them I believe, and this point is driven in by especially victor, that every question all individuals all individuals, the individual that's how their questions were phrased, that's been my observation. But -- now that I have.

Female Speaker: I'm not sure you were not finished.

Male Speaker: No need to apologize, we are on the same team here.

Male Speaker: I would like to go back to some comments that Gail made, I'm on your

side so don't be afraid.

Female Speaker: Gail is too old to be afraid.

(Laughing)

Male Speaker: Maybe we need to advocate at the legislative level, I agree, we should not be afraid to challenge DDDS with that, because Marissa, I know you are in the room I'm not going to act like you are not -- but to challenge them is to actually to help them. When it comes to funding. I know Marissa doesn't see it like that and Jane, if we win,

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they win.

Female Speaker: When I was a division director I saw it that way.

Male Speaker: You should.

Female Speaker: If somebody got up and said she need extra, Gail and I were very

happy.

Female Speaker: And I agree, but it doesn't belong in here.

Male Speaker: I think every opportunity you can talk about that stuff you talk about it.

Female Speaker: Right, if there's another form to do this, but thank you.

Male Speaker: I disagree, every chance you get to talk about that stuff you talk about

it.

Female Speaker: We can talk about it and we can say something, but it doesn't

belong on this form.

Male Speaker: I disagree. Female Speaker: I disagree.

Male Speaker: That's fine. That's how people get educated, the people making the decisions are the ones reading these forms, no reason not to put ideas, I respectively disagree with you on that, the deadline, I understand the need for deadlines -- very few of mine do I meet but I don't think a deadline is a reason to put forth incomplete work. And I'm not saying the work is incomplete, the list of things you are going to challenge next week, that's a pretty healthy task. I'll be here for that, I'll try to be here for that, and the look behind my comments are the same thing with the survey consistency, who's going to be the one coming behind and looking behind, in new castle county Social Security going to be one person --

(Inaudible)

Female Speaker: I think this is too important to not have the same person.

Male Speaker: Applying that look behind philosophy -- and I welcome the opportunity to discuss anything and respond to my questions.

Female Speaker: One of the things to that point in the look behind there needs to be training done by the surveyors so there is consistency, they are going to be looking at different things each provider, they may all answer the question but they are going to look very different and if the person isn't trained to know what to look for.

Male Speaker: Well, the they think with that look behind is, all of the providers in Delaware are different it's one thing to judge vanilla and chocolate ice cream, when you start walking around to different providers in our state and cater to different populations and different needs, one size doesn't fit all, does not. Like I said I appreciate the opportunity to discuss all of this, ask me any question you want to ask and I will disagree with you.

Female Speaker: We don't mind.

(Laughing)

Male Speaker: We are concerned about the people we serve that's what it's all about.

Female Speaker: That's right.

Male Speaker: Thank yous for the opportunity.

Female Speaker: Thank you.

Female Speaker: I will be quick, it relates to Angie's concern and it may not have a place with the assessment, what I'm concerned is about safeguards, somewhere there's a statement about safeguards, especially with do not have anyone no guardian, no

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family member to speak with them or to plan with them I'm not sure what I'm meaning, safeguards or -- be pushed to make a choice they didn't want to make or understand which relates to the -- I have a new job and he did not understand that held not go to the bank anymore.

Male Speaker: That's a very good one.

Female Speaker: So. To go to that savegards is the word I think, but I will look at

this and see where it might fit into some of these.

Female Speaker: Protection --

Female Speaker: Maybe that's the directions.

(Talking at the same time)

Female Speaker: Inappropriate -- before I was a guardian, I was his advocate and sister and I was closed out to a very series of decisions.

Female Speaker: You know this is going back here again in the directions and I think it has to be in the directions somewhere, we can say that whoever is the legal guardian has to be doing these things but to say that and to make sure that the provider is making that, taking that extra step to make sure that's occurring, is another thing.

Female Speaker: I think it's even more potential -- really want to self-advocate as

much as we can --

(Inaudible)

Female Speaker: There's a point where I don't need to be here.

Female Speaker: But, what are we going to do about the middle ground that is a

nebulous place on the border where my brother.

Female Speaker: And I'm not going to live forever --

Female Speaker: And I don't have children.

Female Speaker: We don't have parents and guardians that don't make the right

decisions all the time, and I can say that being the parent.

Female Speaker: Jane did discuss -- I was with her about having representatives, people who are not family members, maybe training, I'm thinking about, I don't want to scare every, but special advocates, not going that far but maybe volunteers become advocates and get training and then can help the person and it's something the director brought up, like the educational surrogate.

Female Speaker: Kind of yeah.

Female Speaker: But they have those because they are not developed yet, so you

are in another realm, and they are adults and can make their own decisions.

Female Speaker: If they can't.

Female Speaker: They would have a guardian if they can't.

Female Speaker: Sometimes they don't because the public defender doesn't have

another capacity.

Female Speaker: It was something Jane recommended.

Female Speaker: Do you think that might be related to the support of decision making

kinds of activities much the.

Female Speaker: I'm not real clear when supported decision making activities, it might be, maybe that's where she's coming from.

Female Speaker: That may be.

Female Speaker: One of the other things that CMS has become very clear, a con political free case manager and that's the expectation is that conflict free case manager

should be insuring that the person's voice and choice is held to the highest degree, so they would be the individual's advocate.

Female Speaker: If there is -- Female Speaker: One of them.

Female Speaker: Right.

Female Speaker: This is Angie, again, I will say, in thinking and listening here, that even Jacob's family supports specialist and others have come in and said you need to do this or that and they will say Jacob doesn't need to be there. So I am his legal guardian, but when you do those things, you don't, you know, you assume that the legal guardian, you don't give the individual any ability at all to participate in those things so there are, I don't know it's just -- murky murky.

Female Speaker: It's true, if the person has a legal guardian, the -- but you know, as the legal guardian, if you want Jacob to be there, then Jacob can be there.

Female Speaker: I feel, this is Lisa, my sense in the trenches here, is that caregiver, the community, everyone contributes we are on his team, most of the time he feels he decide, like I said, I know it's a very serious decision like where to live and that's a more emotional level, but it seems to work and my concern is that there's some legal recourse or regulation recourse for people who might get caught up in the dangerous situation.

Female Speaker: Can be taken advantage of and don't have the capacity to understand.

Female Speaker: I will lay it on the table, inner I can's situation, the DDDS case managers are the ones who create the trouble, manipulated him that he wanted to do certain things, scared him, he wound up in the hospital for a week, there needed to be some other help than that particular individual or better training or accountability for the people who are supposed to be doing it.

Female Speaker: Accountability is huge. **Female Speaker:** It is huge, that's the A word.

Female Speaker: I agree.

Female Speaker: I think these are all issues that are very acute to everyone here. And I think a lot of you have a forum when you do discuss these things and a lot don't, the things you really need to discuss, I don't think as a community, we're going to fix the system here, but it certainly helps to be able to voice those things that are seriously concerning as family or loved ones or providers. I can say, I get clients and I can't get information whether they are their own guardian or the parents are the guardian, that happens to me, on the other hand I sit at tables with parents who say of course I'm their guardian they live with me, then I'm sort of -- so you know, these are all things we deal with in this system on a day-to-day basis, and we would like to solve all of those they thinks at this committee, but I doubt we are going to have the opportunity to, so at least we can air some of them.

Female Speaker: Even the CMS can declare that this is all budget neutral, do you know how ridiculous that is and to somehow divorce it from the cost associated -- in order to implement this is ridiculous, so I will agree with both of you, there is a place for including something maybe not in the self-assessment but some statement somewhere we should be acknowledging the fact that this is going to cost additional money. Just as we did in the task force -- it was just issued on the quality standards, we included a paragraph at the end of that saying that it has to be acknowledged that it's going to

require additional funding.

Female Speaker: And those --

Female Speaker: Who's working on the directions is that you? Who said they would write something up about that? If he wants to send me something, maybe we want to put at the end of this that we would like to acknowledge that we are in agreement that there's a cost attached to this and we recognize, yada yada.

Female Speaker: I don't think we are telling them something they didn't know.

Male Speaker: But we still need to tell them.

Female Speaker: We are under funded and to take on additional programs and thinking that we're going to move people into the community with the moneys that we have currently, is not going to happen, for the majority of our folks. And you know, all we're doing is setting very high expectations with very little resources and support, so I think it has to go somewhere. We can't dance around it.

Female Speaker: I would, do you want me to put that question back in.

Male Speaker: Somewhere.

Female Speaker: Funding will be addressed in the directions?

Female Speaker: We can make a recommendation.

Female Speaker: Remember, next week is voting up or down that's what we are doing, so well have a vote, do we want to put something at the end of our e-mail to DDDS that says as a committee, we want you to be aware that there is a cost attached to this.

Female Speaker: In the e-mail not in the assessment.

Female Speaker: That's what I thought you were talking about.

Female Speaker: I think we decided it's not part of the assessment.

Female Speaker: So we are stating the obvious in an e-mail.

Female Speaker: So we are stating the obvious in an e-mail.

Female Speaker: And without the funding, what's going to happen?

Female Speaker: It's Marissa S I'm going to say that CMS has required and the division welcomes any comment feedback about the entirety of this process. So it doesn't have to be that you only include this in a footnote, but certainly if people want to send in letters commenting on the process, we obviously have expressed an interest in receiving that and well continue to express an interest.

Male Speaker: Who's attention does that go do?

Female Speaker: Me, Jane -- Male Speaker: Very good.

Female Speaker: One of the other things. **Female Speaker:** Cc: Your legislators.

Female Speaker: Some of the other things that were out of the realm of the providers, I think they also need to be addressed -- we are all being assessed and -- and we all work with short resources we strive to do the best we can -- when you talk about the essential lifestyle planning, person center plan, those are key important issue that is this group has talked about them so much they need to be visible somewhere. From the guest and from this committee, there's some footnotes that we would like to add that's not part of the assessment but it will be an up and down vote, so some people, we won't be able to build consensus on that, we won't have time, think about those things, one is the money, one is the responsibility about -- DDDS' role in making sure this all ends up. Okay --

Male Speaker: This is bill. I have listened for the past two hours, you guys look, really, you got the project almost done. Residential still has about 12 questions to go and they fight about every one of them, I don't know whether we are going to get it done, they say it's -- I don't think it's going to happen but it could roll into next week, tomorrow and next week, and we can get it all done, the way you did it is outstanding, we don't, we haven't done that even though I have that well be doing it that way.

Female Speaker: That was my understanding, yes.

Male Speaker: But what I got yesterday was written out, you have to write everything

out. So --

Female Speaker: You are right, we do rock. **Female Speaker:** We are peace loving people.

Female Speaker: My final peace is since we did get so far and did so well, let's work as a committee together and get this figure you had to everyone's satisfaction so we all feel good about what we are turning in that's my biggest wish that everyone feels good about what's turned in, let's try to do the same when we try to accomplish the rest of that, I know Gail and TC are going to make that happen.

Female Speaker: Because we really do rock.

(Laughing)

Female Speaker: Are we done?
Female Speaker: We're done.
Female Speaker: No last words?
Female Speaker: We're done.